

# The CDC Epilepsy Program's activities in response to recommendations from 2012 IOM report on epilepsy

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Centers for Disease Control and Prevention

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## Outline

- ❑ Data collection with regards to the burden of epilepsy
  - Focus on the recommendations 1-4
- ❑ Managing Epilepsy Well Network (MEW network)
  - Focus on the recommendation 3, 4, 8 and 9
- ❑ Important research gaps in epidemiological study
- ❑ Collaboration with Epilepsy Foundation and other organizations
  - Focus on other recommendations

## 2012 IOM Report recommendation 1

- ❑ The CDC, in collaboration with professional organizations, should fund demonstration projects to validate and implement standard definitions and criteria for epilepsy case ascertainment, health care and community services use and costs, and quality of life measurement

## Activities in response to recommendation 1

- ❑ A validation study for questions that were designed to identify lifetime and active epilepsy, medication use, and seizure occurrence on population-based surveys

Brooks DR et al. *Epilepsy Behav.* 2012 ;23(1):57-63

- ❑ Validation of case ascertainment criteria to identify incident and prevalent cases of epilepsy using ICD-9 based algorithms

Selassie AW et al. *The South Carolina Epidemiological Studies of Epilepsy and Seizure Disorders.*

Medical University of South Carolina, Charleston, South Carolina, 2014.

- ❑ Developing and validating methods of natural language processing system using machine learning algorithms to detect “regular expression “ of epilepsy or epilepsy-related issues from electronic medical records for epilepsy case identification and health care

Barbour K et al. *Epilepsia*, 2019 (submitted); Grinspan ZM et al. *Epilepsia*, 2019 (in progress)

## 2012 IOM Report recommendation 2

- ❑ The CDC should continue and expand its leadership in epilepsy surveillance and data collection efforts, and surveillance efforts should be funded that use large, representative samples to determine the overall incidence and prevalence of epilepsy—and mortality—over time as well as in specific populations

## Activities in response to recommendation 2

### □ Epilepsy surveillance using nationally representative samples

- National Health Interview Survey (NHIS)---Included 5 validated epilepsy questions since 2010
  - Have you ever been told by a doctor or other health professional that you have a seizure disorder or epilepsy?
  - Are you currently taking any medicine to control your seizure disorder or epilepsy?
  - Think back to last year about the same time. About how many seizures of any type have you had in the past year?
  - In the past year have you seen a neurologist or epilepsy specialist for your epilepsy or seizure disorder?
  - During the past 30 days, to what extent has epilepsy or its treatment interfered with your normal activities like working, school, or socializing with family or friends?

## Activities in response to recommendation 2 (cont.)

### ❑ Prevalence of active epilepsy in the U.S. and U.S. states

#### ■ Data Used:

- 2015 NHIS data (adults, aged  $\geq 18$  yrs)
- 2011-2012 National Survey of Children's Health (NSCH) (0-17 years)
- 2015 Current Population Survey data

#### ■ Results:

- In 2015, 1.2% of the U.S. population (3.4 million persons: 3 million adults and 470,000 children) reported active epilepsy or current epilepsy
- Numbers of persons with active epilepsy, after accounting for income and age differences by state, ranged from 5,900 in Wyoming to 427,700 in California

## Activities in response to recommendation 2 (cont.)

- ❑ **Epilepsy mortality surveillance / study using statewide representative samples**
  - SUDEP surveillance in the Sudden Death in the Young Case Registry (SDY)
    - SUDEP in children from birth to <20 years of age
    - Starting from 2015, SUDEPs are collected in 10 states/jurisdictions. Now it expands to 14 states/jurisdictions
    - Complicated algorithm to diagnose SUDEP or possible SUDEP through child death review and advanced review teams with multidisciplinary experts including neurologists/epileptologist
    - 40- 50 cases have been identified and SDY system is about 3 times more sensitive to detect SUDEP mortality rate than previous published systems or methods
  - Suicide among people with epilepsy
  - CDC-conducted study using U.S. National Violent Death Reporting System (NVDRS) in 17 U.S. states, 2003-2011---published in 2016



## Activities in response to recommendation 2 (Cont.)

### □ Epilepsy in other specific populations

(national, state or community population-based representative samples)

- Epilepsy in Medicare and Medicaid recipients
  - CDC-supported state and national studies---published in 2012, 2015 and 2018
- Rare epilepsy in children
  - In collaboration with Cornell University and four other medical centers in New York City, coverage of 3 million population, 2015-2018.
  - Data were collected from New York City Clinical Data Research Network
  - 1 million clinical notes of Electronic Health Records have been collected. Rare epilepsy prevalence and incidence data is planned to be published this year
- Epilepsy among Veterans
  - Epilepsy Among Iraq and Afghanistan War Veterans - United States, 2002-2015. MMWR Morb Mortal Wkly Rep. 2016 Nov 11;65(44):1224-1227

## **2012 IOM report recommendation 3**

- ❑ The CDC should partner with other agencies and stakeholders to develop and evaluate prevention efforts for epilepsy and its consequences
- ❑ The IOM report especially addresses three major known risk factors such as neurocysticercosis (NCC), traumatic brain injury (TBI) and stroke for epilepsy prevention

## Activities in response to recommendation 3

- ❑ Developing a tool to detect NCC
  - The CDC has been supporting lab in our agency or commercial labs to develop an easy-to-use ELISA kit that can be used in the field with high sensitivity and specificity to human taeniasis coproantigen
- ❑ Studying on epilepsy-related TBI
  - CDC-supported South Carolina statewide, population-based studies--published in 2014
- ❑ Studying on epilepsy-stroke relationship
  - Statewide, population-based studies in other states---published in 2014 and 2015

## **2012 IOM report recommendation 4**

- ❑ The AES and the American Academy of Neurology (AAN) should lead a collaborative effort with other organizations including CDC to improve the early identification of epilepsy and its comorbid health conditions

## Activities in response to recommendation 4

- ❑ To promptly diagnose epilepsy and its comorbidities and improve access to epilepsy specialty care for people with epilepsy are major goals identified in National Healthy People 2020 objective for epilepsy
- ❑ The CDC continually monitors the percentage of adults who accessed specialty care by using NHIS data
  - Reports observed that only 52.8% of adults with active epilepsy in the US reported seeing a neurologic specialist in the preceding 12 months in 2010, and this number increased to 65.6% in 2010-2014 and 67% in 2015

CDC. MMWR. Morb Mortal Wkly Rep. 2012; 61(45):909-913

Cui et al. MMWR Morb Mortal Wkly Rep. 2015 / 64(43);1209-1214

Tian et al. MMWR Morb Mortal Wkly Rep. 2018 Apr 20;67(15):437-442)

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# Epilepsy Self-management and MEW network

- ❑ Epilepsy self-management programs
  - To advance the science of epilepsy self-management by conducting research in collaboration with network and community stakeholders, and broadly disseminating the findings
  - CDC leads “Managing Epilepsy Well Network” ( MEW network) through the CDC's Prevention Research Centers to develop evidence for the efficacy/validation of epilepsy self-management programs
  - The MEW Network is a team of people who care about people with epilepsy and their caregivers.

# Collaboration

## MANAGING EPILEPSY WELL NETWORK COMMUNITY OF PRACTICE

### 8 SITES

Case Western Reserve University  
Dartmouth College  
Morehouse School of Medicine  
New York University  
University of Arizona  
University of Illinois at Chicago  
University of Minnesota  
University of Washington

### 3 PARTNERS

Centers for Disease Control and Prevention (CDC)  
Epilepsy Foundation  
American Epilepsy Society

### 2 ASSOCIATE MEMBERS

Emory University  
University of Texas



A map of the United States with several location pins in purple and orange, indicating the geographic distribution of the network's sites and partners across the country.

THE POWER OF  
**COLLABORATION**



A row of silhouettes of people in business attire, representing the collaborative effort of the network members.



## Programs

# Self-Management Programs Developed



## Public Health Impact

### Public Health Science Impact 2014-2018

30

ARTICLES  
PUBLISHED

in peer-  
reviewed journals

25

PRESENTATIONS

at professional  
meetings

47

ABSTRACTS &  
POSTERS

presented at  
professional meetings

## Public Health Impact (cont.)

### Public Health Practice Impact 2014-2018

1,000+

PATIENTS WITH EPILEPSY REACHED

137

FACILITATORS TRAINED

34

COLLABORATING ORGANIZATIONS

#### COMMUNITY

Epilepsy Foundation of Central & South Texas • Cleveland Epilepsy Association • Epilepsy Foundation New England • Epilepsy Foundation of Metropolitan New York • Epilepsy Foundation of Greater Chicago • Epilepsy Foundation of Minnesota • Pleasant Grove Baptist Church • Angels of Epilepsy • Epilepsy Foundation of Michigan • United Way • Big Miller Grove Baptist Church • Epilepsy Foundation of Texas • Epilepsy Foundation of Georgia

#### CLINICAL/ACADEMIC

VAPSHCS Epilepsy Center of Excellence • Georgia Clinical and Translational Science Alliance • National and Scientific Research Center of South America • American Academy of Neurology • University of Texas School of Public Health • Banner University Medical Center • Kessler Foundation • University of Illinois Hospital • NYU Comprehensive Epilepsy Center • Rancho Los Amigos National Rehabilitation Center

#### STATE/REGIONAL

Cuyahoga County Addiction and Mental Health Services (ADAMHS) Board • Texas Department of State Health Services • New Hampshire Division of Public Health Services



Managing Epilepsy  
Well Network



EPILEPSY  
FOUNDATION



AMERICAN  
EPILEPSY  
SOCIETY

The Managing Epilepsy Well (MEW) Network is funded by the Centers for Disease Control and Prevention (CDC) Epilepsy Program. The MEW Network is one of CDC's Prevention Research Centers Program thematic networks.

**For detailed inform about MEW network**

<https://managingepilepsywell.org>

<https://www.cdc.gov/epilepsy/index.html>

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## Some important research gaps

### ❑ For 2012 IOM report recommendation 1

- Validation of non-specific epilepsy-related terms is needed since many invalidated epilepsy synonyms are still used by the public (e.g., “drop attack”, “falling out spell”, and “staring spell)
- Standardization of definitions and criteria for epilepsy surveillance should reflect updated epilepsy definition and exclude those acute symptomatic seizures
- Validation of ICD-code based algorithms for identification of epilepsy should be done in some commercial claim data which include large epilepsy samples

### ❑ For 2012 IOM report recommendation 2

- More epilepsy-related questions should be added into NHIS
- Studies using most recent, large, population-based, U.S. community representative samples to investigate epilepsy incidence are limited

## Some important research gaps (cont.)

### ❑ 2012 IOM report recommendation 3

- Continue to explore the possible risk factors for developing epilepsy, especially among incident cases, and to find disparity in different populations for possible intervention

### ❑ For 2012 IOM report recommendation 4

- Develop and validate screening tests for the early identification of epilepsy in at-risk populations, especially those with developmental disabilities, mental health conditions
- Develop and validate screening tests for epilepsy comorbidities.

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# Public Health Programs with Epilepsy Foundation

- ❑ Promoting epilepsy as a public health issue and implementing public health programs
  - Improving health care provider's education
  - Increasing public awareness/reduce stigma
  - Promoting evidence-based self-management programs
- ❑ Improving awareness of epilepsy-related death and SUDEP with National Association of Medical Examiner and Coroner, American Epilepsy Society, Epilepsy Foundation SUDEP Institute and North America SUDEP Registry

**Middleton et al. National Association of Medical Examiners position paper:**

**Recommendations for the investigation and certification of deaths in people with epilepsy.**

**Epilepsia. 2018 Mar;59(3):530-543**

## Further Information

Reference our website at:

[www.cdc.gov/epilepsy](http://www.cdc.gov/epilepsy)

Contact information:

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## CDC Funded Cornell Project

### ---Rare Epilepsy in New York city: Epidemiology and health outcomes

- ❑ Lack of diagnostic codes for the rare epilepsies make it nearly impossible to identify affected individuals
- ❑ Sophisticated natural language processing system using machine learning algorithms can be trained effectively to classify text documents, including physicians' clinical notes
- ❑ 1 million clinical notes have been collected from five medical centers in New York City to establish a population-based cohort
  - Incidence, prevalence, comorbidities, and mortality
  - Easy-to-disseminate set of “regular expression” to identify rare epilepsies in large multi-institutional studies